

AN 1115 WAIVER REQUEST

PROGRAM FOR ALL-INCLUSIVE CARE FOR CHILDREN (PACC)

FLORIDA



Submitted by the Agency for Health Care Administration

EXECUTIVE SUMMARY

Extensive and continuing attention by Florida's hospice programs and Florida's Children's Medical Services Program in the Department of Health indicates that the services available to children with a life-threatening conditions are not meeting the needs of those children and their families. In fact, a study conducted in 1999 reported that 50% of the hospice programs in Florida felt that the needs of terminally ill children were not addressed to their satisfaction. At that time, only 18 hospice programs of the 36 surveyed provided a full hospice program for children. A review of Medicaid data reveals that only \$1.2 million of a nearly \$53 million dollar hospice budget was spent on children's hospice care.

As a result, The Florida Agency for Health Care Administration (AHCA) formed a public/private partnership comprised of AHCA, Florida's Department of Health (Title V Agency) and Florida Hospices and Palliative Care (FHPC) to address the healthcare needs of seriously ill children.

To date, the partnership was successful in obtaining demonstration grant funding from the Centers for Medicare and Medicaid and second year funding from Children's Hospice International (CHI). Additionally the partnership conducted a summit for children's health care practitioners regarding the program of All Inclusive Care for Children (PACC) and facilitated focus groups with parents/caregivers to determine and validate the need for PACC services. Focus group participants were most concerned with the lack of coordination of services available to provide care for their children, and services that would improve the quality of care available to their seriously ill children, their families and caregivers.

Following the summit and discussions with families and caregivers, the partners developed guiding principles and a program model consistent with PACC philosophy. Those principles are noted below:

- ✓ Care must be jointly coordinated by the Department of Health, Children's Medical Services Network (CMSN) and hospice programs.
- ✓ Care should be provided in the home whenever appropriate and possible.
- ✓ PACC should provide an overlay of hospice support services to the Medicaid benefit package for children.
- ✓ Care provided by institutional facilities should decrease in favor of in-home care.
- ✓ Quality of care for children should improve without increasing the cost of care.
- ✓ The family/caregiver is the unit of care.
- ✓ Care will include a medical home for each child that is inclusive of the American Academy of Pediatrics standards of being accessible, continuous, comprehensive, family/caregiver centered, coordinated, compassionate and culturally effective.
- ✓ Enrollment in PACC will be voluntary.

The target population for the PACC demonstration project consists of children enrolled in the CMS Network (CMSN) and who are eligible for Medicaid. CMSN is statutorily charged with the responsibility for caring for children under 21 years of age with special health care needs whose

serious and chronic physical or developmental conditions require extensive preventative and maintenance care beyond that required by typically healthy children. The CMSN operates under an approved 1915 (b) (1) waiver. The CMSN estimates that there are in excess of 300 children who die each year that could benefit from hospice support and palliative care. Many more children have life threatening conditions. Children participating in PACC must be diagnosed with a life threatening condition and be at risk for a death event prior to reaching 21 years of age. A physician must annually certify that the child is at risk for a death event.

Children and families participating in PACC will be eligible for the following benefits:

- ✓ Medicaid benefit package for children
- ✓ Joint collaborative care planning
- ✓ In-home respite
- ✓ Family/caregiver, individual, group counseling
- ✓ Support therapies
- ✓ Bereavement support
- ✓ Palliative care consultation (pain and symptom control)
- ✓ Volunteer support
- ✓ Hospice in-home nursing

Initially, PACC participation will be limited to 8 hospices serving metropolitan, urban and rural areas in Florida. Following implementation, the partnership anticipates statewide expansion based on evaluation outcome data. The partners steering committee developed standards and requirements to be met by hospices prior to participating in PACC. Examples of significant requirements are noted below:

- ✓ Existence of an established pediatric program or a business plan to develop a pediatric hospice program
- ✓ A service delivery partnership with the CMS area office(s) and a children's hospital or a hospital pediatric program
- ✓ Creation of a local advisory council
- ✓ Compliance with pediatric hospice care standards (Children's Hospice International and American Academy of Pediatrics)
- ✓ Development of a joint implementation plan between local CMSN (Title V) and hospice.
- ✓ Ability to sustain financial risk
- ✓ Commitment to participation in evaluation

Through PACC, children receiving curative care will receive PACC support services. When curative care is not attainable, PACC families may choose between PACC as an overlay to the CMSN medical model with care directed by the child's primary care physician and/or specialist or transition to full hospice whereby all services are directed by the hospice.

AHCA is accountable for program implementation, management (fiscal and programmatic) as well as quality control. Annual program monitoring will be conducted by AHCA, CMSN and FHPC.

Program direction is provided by AHCA, which collaborates with a project Steering Committee that includes representatives from each of the PACC partners. AHCA is further supported and guided by the program advisors that include physicians and providers representing children's hospitals, American Academy of Pediatrics, hematology/oncology programs, perinatal programs, pediatric HIV/AIDS programs, Medicaid, CMS medical directors and family/caregiver representatives through the Florida Institute for Family/caregiver Involvement.

Uniform training will be provided for all CMS and hospice programs participating in PACC. Florida is involved in reviewing the Children's Hospice International PACC curriculum that is currently under development. A state specific curriculum will be developed under contract with FHPC to dovetail with the national curriculum.

AHCA is working with the Institute for Child Health Policy (ICHP) in developing an evaluation methodology and strategy that will include analysis of claims data for cost neutrality, utilization, satisfaction and change in functional status/quality of life. ICHP is a data warehouse for children with special health care needs from Florida as well as other states. The Institute also performs all evaluations for the states' Child Health Insurance Program (Florida KidCare).

In June 2002 the PACC project and model was officially named Florida's Partners in Care Program (PIC). The motto for the program is, "Together for Kids". The flower depicts the child, the roots the family/caregiver and the three leaves represent each of the three PIC supporting partners in care: the Agency for Health Care Administration, the Department of Health (CMSN), and the Florida Hospices and Palliative Care Association.



This document will refer to PIC when referencing the Florida PACC model and will use PACC when referring to the federal Program for All Inclusive Care for Children.

TABLE OF CONTENTS
PARTNERS IN CARE PROGRAM (PIC)
A PROGRAM FOR ALL-INCLUSIVE-CARE FOR CHILDREN (PACC)

I.	Public Notice.....	7
II.	The Environment.....	8
III.	The PIC Model.....	11
	A. Overview	11
	B. Care Coordination.....	13
	C. Site Selection.....	13
	D. Implementation Plans	13
	E. Eligibility and Enrollment.....	14
	F. Services and Benefits	15
	G. Referral.....	17
	H. Program Administration	18
IV.	PIC Service Delivery Network	19
V.	Reimbursement	20
VI.	Evaluation	21
	A. Study Purpose	21
	B. Study Questions.....	21
	C. Sample Section.....	22
	D. Data Sources and Measures	22
	<i>Health Care Use Measures</i>	<i>22</i>
	<i>Child and Family/caregiver Functioning.....</i>	<i>23</i>
	E. Data Collection Steps	26
	F. Data Analysis	26
VII.	Training and Outreach	26
	A. Physician Training and Outreach.....	26
	B. CMSN/Hospice Specific Training.....	26
VIII.	Advocacy and Family/Caregiver Centered Care	28
IX.	Quality Management Review	29
X.	Advisory Councils.....	30
XI.	Long -Term Vision	31
XII.	Baseline Data.....	32
XIII.	Attachments	
	I. Medicaid Hospice Data	
	II. Care Coordination Guidelines	
	III. Utilization Data – 1994-1999	

FLORIDA PARTNERS IN CARE PROGRAM (PIC)

A Program for All-Inclusive Care for Children (PACC)

Mission:

To enable children with life-threatening conditions and their families to have an enhanced quality of life through an accessible, continuous, compassionate, comprehensive, culturally sensitive and family/caregiver centered support system.

Vision:

To identify and remove barriers that prohibit access to compassionate, comprehensive, coordinated services, including both curative and comfort care and to support the quality of life and comfort for all children with life-threatening conditions and their families. To support the families and caregivers of these children as they work to manage their lives given the circumstances brought about by the child's illness.

Values:

- Accessible
- Family Centered
- Compassionate
- Coordinated Care
- Culturally Sensitive
- Fiscal Integrity

Intent and Purpose:

The purpose of PIC is to create a partnership for the development of a coordinated, seamless system of care for children with life-threatening conditions that add an overlay of palliative care and support services to an active medical treatment model. The Florida partners include the Agency for Health Care Administration (Medicaid), the Florida Hospices and Palliative Care Association, and the Children's Medical Services Network (CMSN) in the Florida Department of Health. The CMSN is a comprehensive health care delivery system for children and youth with special health care needs.

The purpose of this research and demonstration project is to develop a coordinated system of care that can be evaluated for quality, efficiency, utilization, satisfaction and fiscal impact.

As a result of this demonstration project, Florida will be able to plan for statewide expansion of PACC/PIC to extended population groups in the future based on accurate baseline data and evaluation information.

FLORIDA PARTNERS IN CARE PROGRAM (PIC)

A Program for All-Inclusive Care for Children (PACC)

I. Public Notice

In an effort to provide an overview of the planning and development activities for the Program for All-Inclusive Care for Children, the Florida Agency for Health Care Administration (AHCA), Department of Health's Children's Medical Services Program (CMS), and the Florida Hospices and Palliative Care organization (FHPC) sponsored a summit on February 22, 2001 at Hospice of West Palm Beach. Attending the summit were over 85 health care providers and organizations that provide care to children with life threatening or terminal illnesses, such as children's hospitals, hospices, the Florida Pediatric Society, the Florida Association of Family/caregiver Medicine Practitioners, Regional Perinatal Intensive Care Centers, and children's advocacy organizations.

Ann Armstrong-Dailey, of Children's Hospice International, was the keynote speaker and provided the history of the Program for All-Inclusive Care for Children and an overview of Children's Hospice International. Bob Maryanski from the AHCA and Jayne Parker from CMSN provided the state's perspective while Tim Bowen, representing the hospice organization presented the viewpoint from the hospice perspective. Panel discussions were held by the presenters to provide an opportunity for questions and to advise the various constituencies of how they can affect improved care to children with life-threatening conditions and their families or caregivers.

As project planning has progressed, updates have been provided to the hospices, CMS area offices located throughout the state as well as AHCA's field offices. In addition, the associated children's hospitals and the eight hospices that committed to participating in the demonstration project reaffirmed their support of these efforts.

In addition PACC was featured electronically through AHCA and DOH Internet and intranet sites viewed by an estimated 5,000 people. The Department of Health featured a PACC article in their widely distributed Health Advisor. The Agency for Health Care Administration featured PACC in their publication, Vital Signs. The same publications were printed in hard copy and distributed to the public, providers, staff, and government officials. The Florida Institute for Family/caregiver Involvement featured PACC in two editions of Special Addition. An estimated 700 staff and families having children with special health care needs accessed the PACC articles. PIC will continue to link with families through quarterly editions of Special Addition. Additionally, Florida was invited to present and participate at the request of Children's Hospice International in three congressional receptions relating to PACC. Mr. Bob Maryanski presented the Florida project at each of the receptions.

The draft model for PIC was distributed for review and comment statewide to all hospice programs, CMSN programs and AHCA regional offices for input prior to the development of the III5 waiver. Comments were reviewed and taken into consideration as the waiver document was developed. Additionally the same programs also had the opportunity to review the waiver document.

On August 2, a public notice of the intent to submit the PACC/PIC waiver was published in the Florida Administrative Weekly. The notice allowed 15 days for public opinion and comment.

In addition all three partners have provided on-going public information regarding the PACC demonstration project. Specific efforts include the following:

- *Children's hospice grant awarded to Florida*, Special Additions Newsletter, February 2001.
- *Florida selected for CMS demonstration project*, Department of Health Advisor, Sept-Oct, 2001.
- *Program for all-inclusive care for children*. Presented at Department of Health Quality Management Showcase Meeting, September 6, 2001, Tampa, Florida.
- *PACC grant update*. CMS Network Advisory Council Meeting, July 20, 2001, Tallahassee, FL.
- *Program of all-inclusive care for children- PACC*. CMS Network Statewide Nurse Director Meeting, December 5, 2001, Tallahassee, FL.
- *Hospice support for children with special health care needs*. CMS-Public Health Meeting, May 6, 2002, Tallahassee, FL.
- *Florida's terminally ill children to benefit from new hospice care program*, AHCA Vital Signs, July 2001.
- *PACC Updates*, presentations at the following Florida Hospices and Palliative Care board meetings: January, March, May, September, November, 2001 and January, March, May, 2002.
- *Florida PACC model*. Presentation to hospice program managers, March 1, 2002, Orlando, FL.
- *Hospice News Network*. Electronic Newsletter sent to all professional hospice members in the state of Florida. PACC information included at least quarterly.
- *Congressional Receptions*, presentation to members of Congress and staff in coordination with CHI and CMS, February, 2000; June, 2001; May, 2002.
- *Florida Administrative Weekly*; statewide public notice, August 2, 2002.
- *The Right Care for Children with Life-Limiting Illnesses-PACC Project*, Florida Hospices and Palliative Care 18th Annual Symposium, August 26, 2002.

II. The Environment

The Florida Medicaid Program offers hospice services to children and adults. Medicaid hospice services are not available in Florida to children solely on the basis that a child has a life threatening condition. These services are limited to recipients whose life expectancy is six months or less if the disease runs its normal course. Pursuant to policy and legal requirements, Florida Medicaid's stated purpose for hospice services is to provide palliative health care services to terminally ill recipients when they no longer choose to pursue curative care medical treatment. These rigid restrictions of program and eligibility requirements present a barrier to children with life-threatening illnesses in accessing care that would improve their quality of life and possibly alleviate prolonged suffering and pain. A review of data provided by Florida's Title V (CMS) program indicated that there were in excess of 300 CMS children who die each year from chronic illnesses that could benefit from palliative care including emotional, spiritual, social and educational support to both patient and caregivers. However, due to these restrictions eligible Medicaid recipients seldom access these types of services. A review of Medicaid claims data reveals that approximately 115 Medicaid children (ages 0-19) elected to participate in hospice in fiscal year 1998/99 with total expenditures amounting to \$1.2 million of the \$53.4 million in overall hospice category. Yet, over 2,799 children (ages 0 – 19) died during 1998. In

fiscal year 1999/00 only 105 children accessed Medicaid hospice services expending only \$906,649.

Since 1929, Florida has continued developing a comprehensive statewide system of care for children 0-21 years of age with chronic conditions through the Children's Medical Services Program, a strong public-private partnership. In 1996, the CMS Network was directed in legislation to be made available to Medicaid (Title XIX) children with special health care needs as a Medicaid managed care choice. The term children with chronic conditions changed to "children with special health care needs" and a statutory definition of these children has been created at both the state and federal levels of government. In 1998, the CMS Network was authorized to expand its managed system of care to children with special health care needs under Title XXI of the Social Security Act, through Florida's Child Health Insurance Program (CHIP). In addition, the CMS Network continues to serve children with special health care needs through the Safety Net Program for eligible children who do not qualify for Medicaid or Title XXI.

Today, the CMS Network includes a full continuum of services with access to prevention and early intervention programs, primary care, specialty care, medical foster care, medical day care, in-home wrap-around and other services for medically complex/fragile children;(www.cms-kids.com). The CMS Network is a primary care physician model whereby each child has a primary care physician that is a board certified pediatrician or family medicine practitioner who authorizes or provides all services and is the child's medical home in accordance with American Academy of Pediatrics Medical Home standards. The benefit package is the Medicaid benefit package for children, including any medically necessary service.

The CMS Network is authorized in: 1) Chapter 391, F.S.; 2) Chapter 409.810 through 409.820, the Florida Kidcare Act /CHIP, establishing the CMS Network as a program for children with special health care needs covered through Title XXI of the Federal Social Security Act; and 3) Chapter 409.9126 authorizing the CMS Network as a Medicaid choice for children with special health care needs under an approved federal waiver. The CMSN is operational through an approved 1915(b)(1) MediPass Waiver for the Medicaid population with special health care needs. This waiver assures access to care, quality services, cost effectiveness and efficiency. The CMSN currently serves approximately 40,000 children with special health care needs.

In addition, the CMS Program is Florida's designated Title V Program for Children with Special Health Care Needs. Section 501 of the Social Security Act enables each state to:

- ✓ Provide rehabilitation services for SSI child beneficiaries under the age of 16 to the extent these services are not covered by Medicaid; and
- ✓ Provide and promote family/caregiver-centered and coordinated care (including care coordination services) for children with special health care needs.

In the early 1960's, most people who did not die suddenly, died in a hospital setting or a nursing home with little opportunity to choose the type of care and quality of care they wanted. Most people died in pain, with little communication from their physicians regarding the terminal nature of the medical events. By the 1970's care for those at the end of life had changed dramatically with the introduction of end-of-life care called hospice. Modeled after a care system developed by Dame Cecily Saunders in England, credited with opening the first "official" hospice in 1967, a small group of volunteers emerged in the United States to deliver care to the dying in their homes. The group emphasized pain management, patient choice, and the involvement of the family/caregiver in the care giving.

The first hospice in the United States opened in Connecticut in 1974. Many people living in the surrounding area near this hospice house had little information regarding hospice care and were uncomfortable with having such a facility in their neighborhood. Not long after, communities began competing for the honor of taking care of the dying, and in 1983 Title 42 was passed into law allowing for the Hospice Medicare Benefit. With the funding source established, hospice workers were able to significantly increase access to all members of the community, and hospices could become operational in small, rural areas as well as big cities, providing adequate support services and help for the grieving family/caregiver after the death. Shortly after the Medicare Hospice Benefit became law, many states adopted a Hospice Medicaid Benefit. In Florida, Medicaid began to pay for hospice care in 1987. Florida was one of the first states to receive Medicaid funds for hospice services. Today 38 hospice programs are organized under the Florida Hospices and Palliative Care Association (www.floridahospices.org).

In 1999, the Florida Hospices and Palliative Care organization surveyed its members regarding the availability of specific hospice programs for children. Eighteen of 38 hospices, or approximately half of Florida's hospices indicated that they provide hospice services with children's specific programming. Hospice programs that do not provide children's programs reported that they rarely receive pediatric referrals, thus a separate program was not justified. Fifty percent of hospices reported that the needs of terminally ill children are not met in their respective service areas. Primary reasons include: children's hospitals generally do not refer to hospice, pediatric physicians often do not see hospice as part of pediatric health care and family/caregiver members are often reluctant to give up aggressive treatment. The push for a cure generally means that less attention is given to symptom control.

To better assess the reasons for not accessing these services, to determine parent and caregiver satisfaction with existing services and to determine the services that could be made available to families with a seriously ill child, focus groups were conducted in Miami, Orlando and Gainesville for parents and caregivers whose children died. Results from parents participating in the focus groups in late July 2001 indicate that family/caregiver members are most concerned with the lack of coordination of services available to provide care for their child. In many instances they did not know whom to turn to for advice or support. Hospice was not considered as an option but rather as a service for the dying, however these parents and caregivers were not prepared to give up hope that the child could be cured. Parents and caregivers unanimously cited the need for respite and emotional support for other family/caregiver members, especially siblings.

Families also expressed the need for resources and information concerning their child's disease. There was agreement on the need for parent-to-parent support groups, to provide emotional support to parents or caregivers whose children had the same disease or illness as their child. Many parents/caregivers received vital information from other parents/caregivers instead of the medical staff caring for their child. Parents and caregivers felt that this source of information would be more helpful if better organized and expressed a strong desire to be contacted so they, in turn, could help other parents/caregivers make more informed decisions. Parents and caregivers repeatedly indicated the need for increased care coordination, case management, respite care and emotional support.

Other repeated issues were the lack of understanding by the pediatric community in terms of appropriately communicating with parents and caregivers regarding issues associated with death, dying and dealing with grief. In addition, focus group members wanted more information

regarding the progression of their child's disease and care that would be required for that particular disease, particularly when their child's medical condition was deteriorating.

The fundamental conclusion drawn from the focus group experience was that the current "system" is a non-system that is fragmented and unresponsive to the special needs of families who have children with life-threatening conditions. However, the components to create a formal system of care currently exist but as separate entities. The focus of PACC will be to bring the medical and support systems together as an integral part of the child's treatment plan.

III. The Model

A. Overview

The Florida Agency for Health Care Administration and its partners (FHPC, CMSN) believes that there is significant opportunity for improving the quality of life of children with life threatening illness through increasing access to an overlay of hospice support services while receiving curative care and, at the same time, decreasing overall health care costs, or at a minimum maintaining a program that is cost neutral. The emphasis of the demonstration project is twofold. First, this demonstration project will be to provide care in the home, decrease the amount of care provided by inpatient facilities, while increasing the child's quality of life. Secondly, this project will increase the opportunity for the child and family/caregiver to obtain necessary and simultaneous psychosocial services. This model recognizes the family/caregiver's ability to make their own choices regarding their care. Through the provision of enhanced psychosocial interventions, the children and families/caregivers should be more capable of handling crises that arise and more comfortable with the child staying at home, thus decreasing hospital admissions. It is further anticipated that the frequency of emergency room visits will decrease. The PACC/PIC demonstration project will provide individualized care coordination of health care, social services and support services for children with life threatening illnesses, from referral or diagnosis through end of life care.

Refer to page 12 for a graphic representation of Florida's Partners in Care (PIC) model.

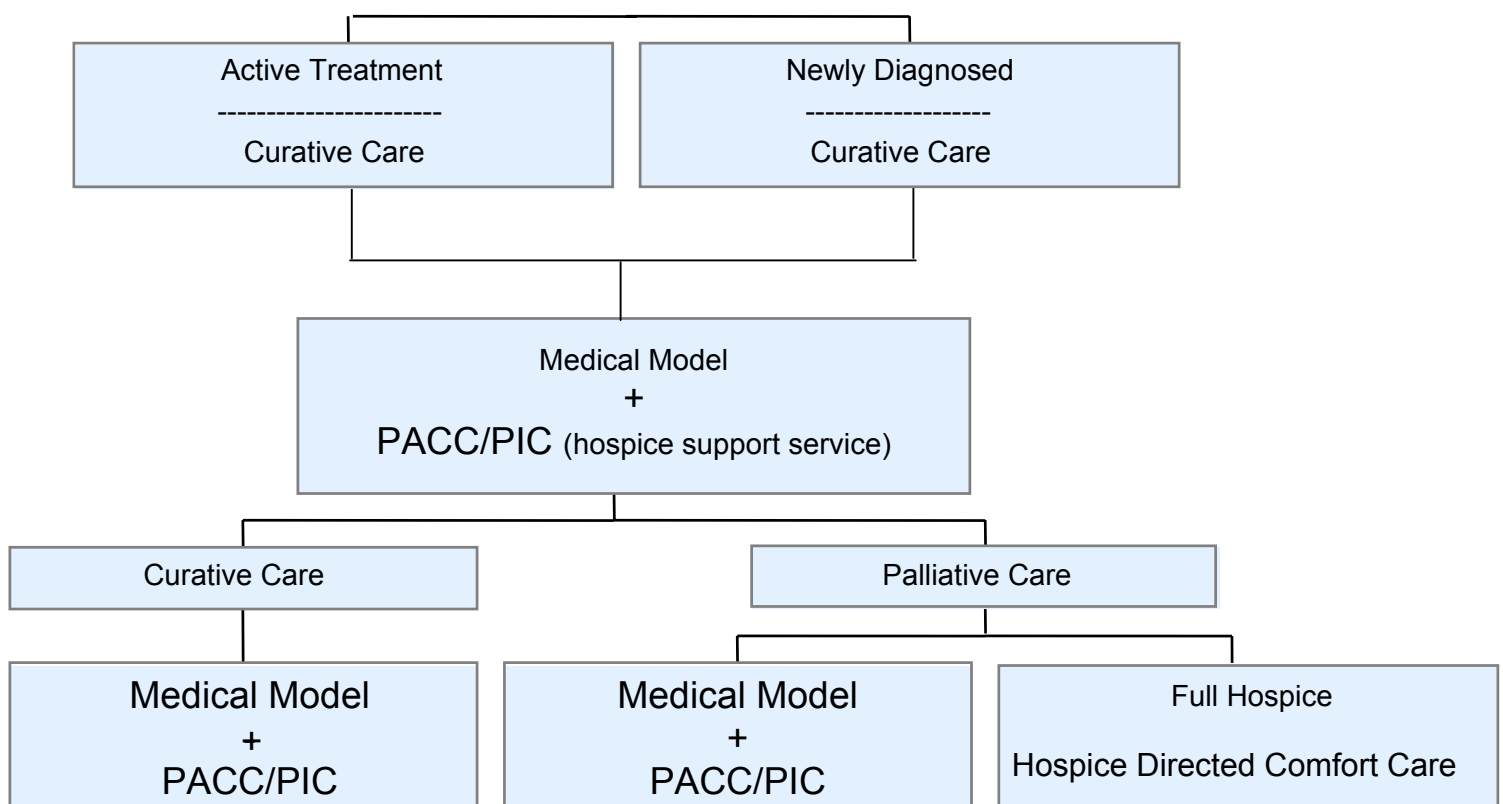
For the research and demonstration phase of the project, children who are newly diagnosed as well as children who are currently receiving active treatment for life threatening condition may be enrolled in PIC. All children will be approved for PIC participation by the child's primary care physician prior to enrollment. Families may choose to participate on a voluntary basis. Coordination of the enrollment in PIC is a function of the child's CMSN care coordinator who is responsible for coordination and enrollment with the participating hospice partner, treating providers and the family/caregiver. Enrollment requirements are predicated on the PIC evaluation methodology page 21-26.

All children enrolled in PIC will receive an overlay of hospice psychosocial and support services in addition to receiving comprehensive medical management and treatment provided through a primary care case management model (PCCM). Services will be jointly coordinated by the CMSN and hospice care coordinators.

Many children will remain in the PIC program, receiving active medical treatment, however, there will be some patients for whom curative treatment cannot be attained. Families will have the choice of remaining in CMSN/PIC or moving to full hospice care without curative care intervention. Under the full hospice palliative care choice the child is disenrolled from the CMSN and the hospice directs and coordinates the care. Families will, however, have the choice to remain in PIC and the CMSN even if curative treatment is no longer an option.

Florida Partners in Care (PIC) Program

- **Children 0 to 21 years**
- **Medicaid/Title V (CMSN)**
- **Enrolled in CMSN (PCCM Medical Model)**
- **Life Threatening Condition**
- **PACC/PIC Overlay Services**



B. Care Coordination

Service and treatment coordination will be critical to the PIC process and will be operationalized through the development of joint care planning between CMSN and Hospice. Attachment II describes the formal care coordination process that will accommodate the addition of PIC services and coordination with local hospice staff. This process will be achieved through the partnering of eight identified CMS and hospice offices located in the following demonstration sites: Largo, Miami, Ft. Myers, West Palm Beach, Jacksonville, Gainesville, Orlando and Pensacola. These 8 sites provide service to over 30 counties and include rural, urban and metropolitan areas of the state as well as an ethnically diverse population. The CMSN and the hospice care coordinators will work in partnership to achieve a seamless system of care for the child. Formal coordination/staffing meetings will be regularly scheduled as prescribed in the child's plan of care.

While in active treatment/curative care, the CMSN nurse care coordination will be the primary care coordinator responsible for maintaining and coordinating the plan of care for the child. When curative care is no longer attainable and the family/caregiver chooses to remain in the CMSN/PIC program, the hospice nurse will assume the primary care coordination role in collaboration with the CMS nurse and family/caregiver.

C. Site Selection

For the eight CMSN and hospice programs participating in the demonstration phase of the project, a scheduled phase-in will be established by the PIC Steering Committee pending the approval of the waiver. Selection for phase-in is contingent upon the collaborative partner's ability to meet the criteria listed below.

- ✓ Existence of an established pediatric hospice program or a business plan to develop specific pediatric services
- ✓ Geographical representation (metropolitan, urban, rural)
- ✓ Ability to sustain financial risk
- ✓ Commitment to provide training to ensure properly trained staff
- ✓ Volume of need within catchment area
- ✓ Creation of system for ethical consults regarding PIC cases
- ✓ Qualifications of staff for delivery of care
- ✓ Strong relationship with a children's hospital or pediatric department within a hospital
- ✓ Plan for informing providers and strategies for encouraging referrals to PIC
- ✓ Creation of a local advisory council with representatives to include CMS medical staff, consumers, and other local health care representatives
- ✓ Demonstration of collaborative working relationship between all partners.
- ✓ Verification that the hospice meets pediatric standards of care as established by Children's Hospice International and the American Academy of Pediatrics
- ✓ Cross-walk to Medicaid/CMSN grievance, complaint and fair hearings processes

D. Implementation Plans

Each demonstration site, in the catchment areas will develop a joint PIC Implementation Plan between CMSN and the related hospice to be submitted to the PIC Steering Committee. Each Implementation Plan will be reviewed and rated in accordance with established criteria that includes but is not limited to criteria specified in Section C. A sub-committee appointed by the

PIC Steering Committee will make recommendations to the Steering Committee on the order in which sites will implement PIC based on scoring outcomes of the respective implementation plans.

The Implementation Plan will include the information outlining how the joint collaborative effort between the hospice and CMS will address all the implementation criteria. The Implementation Plan will include information about the hospice's children's program and service delivery system including a description of the working relationship with the local children's hospital. Also to be requested is a historical perspective of the children's hospice program along with the numbers of children served for the last three years. The hospice and CMS offices will also need to outline how the two organizations have collaborated together and the plan to develop the joint care conferencing. The Implementation Plan will include sufficient information for the Steering Committee sub-group to make appropriate implementation decisions and recommendations.

A request for the Implementation Plan will be sent to the eight demonstration sites during September 2002. Full information regarding plan requirements, deadline dates and where to submit the Plan will be contained in the cover letter sent to each of the eight demonstration sites and will be contingent on the date of waiver approval.

E. Eligibility and Enrollment

Children meeting eligibility requirements for the proposed demonstration project must be enrolled in the Department of Health's Children's Medical Services Network (CMSN) as Medicaid recipients. CMS is charged in state and federal law with providing children with special health care needs a family/caregiver-centered, comprehensive and coordinated statewide-managed system of care that links community-based health care with multi-disciplinary, regional, and tertiary pediatric specialty care. Florida's proposed PACC/PIC model will add an overlay of additional psychosocial and support services to the existing CMSN system of care. PIC services will be provided during the pilot on a fee for service basis in order to ascertain cost and utilization data for future planning and expansion of PIC.

One of the tenets of this new model of care is that the newly created care planning process will provide a seamless delivery system consistent with Children's Hospice International and the American Academy of Pediatrics standards. Additional PIC standards may be developed during the demonstration.

CMSN enrolled Medicaid children who are or have been diagnosed with life threatening conditions, with or without complex psychosocial and familial problems, who are at risk of a death event prior to reaching 21 years of age will be eligible for participation in PIC. The CMS care coordinator will include in the medical, developmental, psychosocial assessment additional assessment information to assess eligibility for PIC services. Each pilot area will be limited to a specified number of children from each of the PIC evaluation groupings due to the amount of Medicaid budget available to support PIC services.

Since the CMS Network is a PCCM model, each child has a primary care physician who provides or authorizes all services for the child. The CMSN care coordinator works in collaboration with the family/caregiver and the primary care physician as well as specialists. The CMS care coordinator, after determining eligibility for PIC services, will contact the child's physician for his/her medical determination that the child is at risk for a death event prior to age 21 and could benefit from PIC services. Families will be offered the choice of participating in

PIC. Upon receiving physician approval, the family/caregiver will be contacted by professional hospice staff that work with PIC to assess the child's needs for PIC services.

It is estimated that approximately 150 children and youth with life threatening conditions will be served by PIC during the demonstration phase of the project unless additional funding is made available to the project. Children enrolled in the PIC pilot will require annual recertification by the child's primary care physician that the child's condition remains life threatening.

Children may be discharged from the PIC pilot program for the following reasons:

- ✓ Family/caregiver income changes resulting in a loss of Medicaid eligibility for more than three consecutive months since the CMSN cannot assume the cost of PIC services
- ✓ Child no longer at risk for a death event
- ✓ Family/caregiver desire to no longer participate in program
- ✓ Family/caregiver elects the traditional hospice benefit for their child
- ✓ Relocation out of PIC pilot areas

F. Services and Benefits

In addition to the full array of Medicaid services for children, the PIC program will add an overlay of the following services:

- ✓ In-home respite
- ✓ Family/caregiver counseling
- ✓ Individual counseling
- ✓ Group counseling
- ✓ Bereavement counseling
- ✓ Pain and symptom control consultation
- ✓ Support therapies
- ✓ Hospice in-home nursing
- ✓ Hospice in-home personal care
- ✓ Volunteer support
- ✓ Joint collaborative care planning

The Florida model is an integrated model whereby PIC supporting services become an overlay to the CMSN medical model. Through a close working partnership between the CMSN and hospice, these services would be included in the child's plan of care through the care coordination process. Frequency, scope and duration of PIC services are being developed in coordination with FHPC and Medicaid. The following is a description of the PIC services that will be provided.

Counseling

Experience in Florida's patient care networks indicates that the emotional state of an ill child has a significant effect on physical health of the ill child and the entire family/caregiver unit. It is well documented that the emotional turmoil of having a life limiting disease can create significant stress, which negatively influences physical health. The provision of services that increase hope, decrease emotional pain and provide spiritual care can significantly increase self-care activities and lessen dependence on medical facilities. It is anticipated that this effect can be achieved through psychosocial counseling of participants and their family/caregiver members. The impact on the family/caregiver unit when a child is the ill family/caregiver member is great.

For this waiver the “family/caregiver” is defined as the child’s parents/guardians, siblings, and extended family/caregiver members such as grandparents or others who have ongoing caregiving responsibilities for the child.

Counseling will be provided by licensed clinical social workers, chaplains, licensed mental health counselors, or licensed marriage and family/caregiver therapists (or registered interns of one of these three disciplines) employed by a hospice in the pilot areas. Hospices will have the ability to provide counseling services in multiple settings.

At a minimum, counseling services will include family/caregiver, individual, and group counseling. Group counseling will include separate support groups for parents/caregivers and healthy siblings. At the time of referral to PIC, participants will receive information regarding all available counseling services. As family/caregiver coping strategies are affected by the course of the disease, it would not be unusual for participants to vary the kind of counseling they receive.

Counseling services are typically offered weekly to the family/caregiver unit. Depending on family/caregiver psychosocial circumstances and choice, counseling may be offered less frequently. The family/caregiver may choose to be seen as a family/caregiver unit or in separate sub-groups such as the parents together, and the siblings separately. If this is the case, the frequency of counseling to the larger family/caregiver unit may be more than once per week. The scope of services will be determined when the hospice counselor meets with the family/caregiver for the first visit. Joint care planning must include the wishes and desires of the child when appropriate and the family/caregiver. Frequency of counseling services will be discussed and approved by consensus during the joint care-planning meeting with the CMSN care coordinator. This will allow the child’s care plan to reflect the scope, frequency, and duration of counseling services. As the needs of the family/caregiver may change suddenly, it will be the responsibility of the hospice counselor to contact the CMS cares coordinator to discuss any changes in the family/caregiver system that may require additional counseling services other than what had been previously discussed and approved. The duration of counseling services will be discussed at the regularly scheduled joint care planning meeting with approval for additional counseling being given during that time. Unplanned and critical needs may be addressed at any point in time.

PIC services may also include therapeutic support services such as music, art, play, pet, and massage therapy. Hospice programs may utilize their own staff or volunteers or contract with other local professionals to provide such services to program participants.

Bereavement Counseling

Bereavement counseling will be offered to program participants who were receiving PIC services. Bereavement counseling will be offered for up to and including twelve months after the death of the child. Bereavement counseling will be provided by licensed clinical social workers, licensed mental health counselors, or licensed marriage and family/caregiver therapists (or registered interns of one of these three disciplines) employed by a hospice in the pilot areas. Bereavement counseling will include individual, family/caregiver, and group support.

Respite

Respite care can be provided when a PIC waiver participant’s primary caregiver is either absent or unable to provide care and the recipient’s condition and need for care require an alternate caregiver for a limited amount of time. In-home respite care will be provided in the participant’s

home, with the alternate caregiver staying in the recipient's home. Providers of respite care will be licensed hospices, home health agencies, or licensed and registered nurses.

Pain and Symptom Control

A percentage of program participants will have unacceptable levels of pain or discomfort from symptoms related to their diagnosis. The child's CMS physician(s) may wish to consult with the hospice palliative care physicians or advanced registered nurse practitioners regarding pain, fatigue and symptom management. The hospice palliative care physician or advanced nurse practitioner may conduct a physical assessment of the child when the CMS physician orders a palliative care consult. The hospice palliative care physician or nurse practitioner will then contact the referring physician to discuss treatment options that can be provided through the CMS network of physicians.

In-Home Nursing

Children in the CMSN are provided care through their primary care physician and other sub-specialists. There may be times when the child's illness requires in-home nursing care. In-home nursing in certain situations may decrease the need for and cost of inpatient care. PIC will provide opportunities for a hospice nurse to make in-home nursing visits to assess and potentially provide care to the child. The hospice nurse will participate in regularly scheduled care conferences as well as communicating with the CMS case coordinator via telephone to report any concerns or change in medical status.

In-Home Personal Care

Children in the CMSN receive their medical care through their primary care physician and other sub specialists. Many children could benefit from the opportunity to have personal care from a home health aide. Parents and guardians have little assistance or support in the ongoing personal care needs of their child. For parents who work outside of the home, it can be extremely difficult to be the sole provider of their child's care. The PIC program will have the ability to offer personal care to children who may need assistance in bathing, toileting, and other self-care needs.

Volunteer Services

Volunteer services are a non-reimbursable service offered through this PIC program. Only trained and screened hospice volunteers would be utilized by PIC. Hospice counselors would coordinate all aspects of volunteer support. This service, as well as all other program services, would be discussed and evaluated at the regularly scheduled care planning conferences between hospice and CMS staff. Volunteers serve an important role and may provide many useful functions to program participants such as mentoring services to the ill child and his/her siblings, child care for healthy children, pet support (such as Project Pup, a pet therapy program), and transportation assistance to hospice service centers for counseling. The hospice programs in the pilot sites may offer additional volunteer services.

G. Referral

The CMSN is responsible for referring children to the PIC Program through a coordinated effort that includes the child's primary physician, specialist physicians and the family/caregiver. Infants, children, and young adults may be referred to PIC from the time of diagnosis or at any point in the treatment process. The child's primary care physician must certify that the child's condition could result in death prior to the age of 21 years and that the child/family/caregiver could benefit from PIC support services. Based upon the family/caregiver's voluntary agreement to participate in PIC, the CMS care coordinator will notify the hospice to initiate a needs

assessment for PIC waiver services. The CMS office will fax a referral to the hospice office on a secure fax machine. The hospice counselor will contact the family/caregiver to assess their particular support needs. Once the initial visit is made, the hospice PIC professional will notify the CMS care coordinator. Upon completing the initial psychosocial assessment, recommendations for PIC support services will be presented to the CMS care coordinator who will incorporate the support services in the child's care plan. Coordination/staffing meetings between the CMS care coordinator, the hospice care staff, family/caregiver members (including child whenever possible), and physicians (if possible) will be held at frequencies determined and documented in the Plan of Care based on the needs of the child and family/caregiver. Frequency may change with the changing conditions of the child.

An emergency after-hour protocol will exist in each eight hospice sites participating in the demonstration project. Hospice will provide after hours availability for emergent support. After hour counselors will be available for telephone consultation and a visit if required. Children enrolled in the CMSN are covered 24 hours a day, seven days a week through their primary care physician. Children who may require emergency medical services would contact their primary care physician or 911.

H. Program Administration

PIC is being developed and implemented through a strong collaborative partnership involving Medicaid (Agency for Health Care Administration), Children's Medical Services (Department of Health), and the Florida Hospices and Palliative Care organization. These collaborative efforts will be maintained throughout the demonstration project as well as during planning for statewide expansion of PIC. Florida Medicaid is responsible and accountable for implementation, management, waiver development and oversight of PIC. The project is directed by a PIC Project Director and a Project Manager who will provide program and policy development, contract management, budget management, federal and state reporting, data and information reporting, program implementation, monitoring, evaluation and strategic planning. AHCA is responsible for staffing the PIC Steering Committee that includes representatives from DOH and Florida Hospices and Palliative Care. Additional advisors to the PIC program include representatives from families, children's hospitals and medical providers from specialty programs such as perinatal, hematology/oncology and pediatric HIV/AIDS. The Steering Committee will receive recommendations from the local PIC advisory groups and respond accordingly. In addition AHCA is responsible for representing Florida at the federal and national levels in regards to PACC/PIC. AHCA currently has two positions on the PIC Steering Committee.

AHCA contracts with Florida Hospices and Palliative Care to coordinate develop and implement key components of the PIC program. FHPC works with a variety of providers and consultants to produce specific contract deliverables. Examples of FHPC work products include collaborative development and implementation of a competency based training curriculum, review of Implementation Plans, development of hospice reporting requirements, recommendations for a fee schedule, monitoring, planning for statewide expansion, development of outreach and marketing materials and participation in steering committee meetings and conference calls. FHPC maintains a major role in developing and delivering a PIC training curriculum. FHPC currently has three positions on the PIC Steering Committee.

The Department of Health is responsible for the interface between the medical model and referral to PIC. They are also responsible for working with each of the CMSN programs included in the pilot to foster and integrate PIC services in the child's care plan through a collaborative relationship with the local hospice programs. The CMSN is responsible for working with the

panel of pediatric primary and specialty care physicians who will be integrating PIC services with the child's curative care plan. A program manager at CMS headquarters is responsible for implementation, training and coordination, and monitoring functions for the CMSN component of the PIC project.

The DOH/CMSN currently has one position on the PIC Steering Committee. DOH contributes to the in-kind match for the PACC grant in addition to providing a full time position to AHCA to serve as PIC program manager. This dual position ensures close collaboration between all of the PIC partners.

A formal administrative and service delivery partnership will be established through the CMSN and the respective pediatric hospice programs in the eight selected pilot programs upon completion and approval of their Implementation Plan. The Implementation Plan addresses the method by which CMS and the hospice will implement PIC in their local areas. Joint responsibilities include developing an Implementation Plan, collecting data regarding PIC services; conducting joint care plan meetings, providing referral and care coordination activities for PIC including coordination of the child's medical care and active treatment, implementation of the child's care plan, coordinating community services, as well as scheduling, meeting, and participating in care plan meetings.

IV. PACC Service Delivery Network

The PACC service delivery network includes the existing CMS statewide network for children with special health care needs working in partnership with local pediatric hospice programs. Hospice support services will be an overlay to the CMSN.

The CMS Program is located in the Florida Department of Health and is directed by a deputy secretary who is a physician licensed to practice medicine in Florida and who has experience in child health programs. The CMSN is established in statute to serve children in Medicaid and Title XXI (Child Health Insurance Program). Services are provided by a panel of over 5,000 approved physicians who are credentialed in pediatric care and who meet specific approval criteria. The CMSN provides the Medicaid benefit package for children. There are currently 26,000 Medicaid children and 14,000 non-Medicaid children with special health care needs enrolled in the CMSN. CMS Services are provided through 22 local service areas staffed by 373 care coordinators who are state employed nurses, social workers and support staff. Each office has a part-time Medical Director who is a local practicing CMSN physician who is board certified in pediatrics. Services are provided locally in CMS clinics or physician offices with access to CMSN approved hospitals, medical centers and providers. Over 140 contracts link medical schools, hospitals, regional medical facilities and providers. CMSN contractual relationships include eleven Regional Perinatal Intensive Care Centers, eleven HIV/AIDS programs and nine hematology/oncology programs affiliated with medical schools, specialty and children's hospitals. CMSN provides individualized care coordination by nursing and social work professionals for each child enrolled in the network. Care coordination includes a formal process of assessment, planning, intervention and evaluation (Attachment II). The CMSN also includes a strong Quality Management component that utilizes quarterly and annual monitoring of service area operations, including numerous performance measures.

Florida Hospices and Palliative Care, Inc is the state organization representing hospice and palliative care providers in Florida. All of its program members are licensed as hospice organizations by the State of Florida through its Agency on Health Care Administration. Additionally, they are all Medicare and Medicaid certified.

Hospice programs provide medical care to terminally ill patients as well as supportive services to patients, their families and significant others 24 hours a day, 7 days a week, in both home and facility-based settings. Medical, social, spiritual and emotional care is provided during the last stages of illness for the patient and during bereavement for the family/caregiver and significant others.

An interdisciplinary team consisting of the patient, the patient's family/caregiver, the patient's physician, hospice professionals and volunteers provide comprehensive care. The Hospice Interdisciplinary Team consists of the following professionals: Hospice Medical Director, Nurses, Social Workers, Home Health Aides, Homemakers, Chaplains, Bereavement Counselors and Volunteers.

Hospice care provides a continuum of care ranging from home care to inpatient care with emphasis on maintaining the patient at home in the most familiar and least restrictive environment. Hospice services are provided to patients and their families; together they are considered the unit of care.

V. Reimbursement

The following PIC services will be reimbursed on a fee-for-services basis through the Medicaid system using specified procedure codes:

- Counseling
- Therapeutic Support
- Respite
- In-home Nursing Care
- In-home Personal Care
- Bereavement
- Palliative Care (Pain and Symptom) Consultation

Local procedure codes will be developed pending the outcome of HIPAA negotiation with Children's Hospice International to establish a generic HIPAA/PACC code. Procedure coding will be HIPAA compliant.

Counseling services will be developed into several components paid at varying rates based on service provider. Volunteer services will not be billed but will be provided under the auspices and supervision of the local hospice. Palliative care physician consultation for pain and symptom control will be billed as a physician consultation under Medicaid State Plan.

Each hospice service site will be allowed to bill for services under the HCFA 1500 form except for bereavement services. The Florida Medicaid Information system is populated with date-of-death data from several sources, including vital statistics. The system will not allow for edits that change this field of eligibility. Therefore, bereavement services will be billed via manual gross adjustment billing at quarterly intervals during the twelve months post death period. Payment requests for bereavement will be made through the PIC program in the Agency for Health Care Administration.

AHCA has agreed to a fund shift of \$1 million from the inpatient hospital and emergency room categories to fund PIC demonstration services in eight selected pilot sites. Each site will receive

authority to bill no more than a total of \$125,000 per twelve-month period of time. It is estimated that PIC related expenditures for children would average approximately \$8500/child/annually. Unmet needs over \$8500/child will be tracked by the hospice program and made available to AHCA and or the evaluator to assess need. This methodology will ensure that a cross section of children will be served during the pilot, ensuring critical utilization data for evaluation and analysis. As a result of this demonstration project AHCA will be able to ascertain the cost per child of children who are newly diagnosed, currently receiving treatment and those who are nearing the end of their course of treatment. In addition, claims data will be available for PIC children who ultimately choose full hospice care for end of life care. AHCA will also analyze the cost for children who are similar in profile but do not participate in PIC. Statewide planning will be based on the collection and analysis of utilization, claims and evaluation data.

VI. Evaluation

The Institute for Child Health Policy (ICHP) is Florida's data warehouse for children with special health care needs. The Institute is fully staffed by health economists, evaluators and analysts. They provide valuable evaluation services for the Maternal and Child Health Bureau, Florida's child health insurance program (Florida KidCare), the Agency for Health Care Administration and Medicaid in other states.

PIC is working with the Institute to develop a mutually agreeable, cost effective evaluation strategy that can be supported through PACC funding. The following is the proposed strategy that may be refined based on budget capability.

A. Study Purpose

The purpose of this evaluation is to assess the relationship between enrollment in the PIC and children's and families' outcomes of care. Outcomes of interest in achieving cost neutrality include: health care use rates and cost for inpatient care, outpatient care, emergency room use, and pharmacy, use rates and cost for supportive care services, families' satisfaction with care, families' functioning, children's quality of life, and adolescents' perceptions of their care. As a result of the demonstration, the State will be able to project a cost for statewide implementation. The evaluation data will provide an important foundation to support expansion.

B. Study Questions

The following specific questions will be addressed in terms of children enrolled in PIC, a control group and a group that was offered but chose not to enroll in PIC:

1. What is the relationship between enrollment in PIC and children's health care use and cost, after considering the children's stage of illness, their illness burden, and their sociodemographic characteristics? The outcome measures include the total health care use rates and cost, outpatient use rates and cost, the odds of emergency room use, the odds of an inpatient stay, and pharmacy use and cost.
2. What is the relationship between enrollment in PIC and families' satisfaction with their children's health care as measured by the selected items from the Consumer Assessment of Health Plans Survey and other items designed to assess care coordination and pain management, after considering the

- children's stage of illness, their illness burden, and their sociodemographic characteristics?
3. What is the relationship between enrollment in the PIC and children's quality of life as measured by the Pediatric Quality of Life Survey, after considering the children's stage of illness, their illness burden, and their sociodemographic characteristics?
 4. What is the relationship between enrollment in the PIC and family/caregiver functioning as measured by selected dimensions of the Child Health Questionnaire, after considering the children's stage of illness, their illness burden, and their sociodemographic characteristics?
 5. How do adolescents in PIC respond to the selected Consumer Assessment of Health Plan Survey items, care coordination items, pain management items, and the Pediatric Quality of Life Survey and the structured interview questions about their children's health compared to adolescents in the control group?
 6. For those children who receive the hospice overlay services (PIC), what is their relationship between enrollment in PIC and parental satisfaction, compared to those in the control group?

C. Sample Section

AHCA has developed admission criteria for the program that include the following approaches. Nurse Coordinators for the State Title V Children with Special Health Care Needs (CSHCN) Program will work with physicians to identify children with life threatening illnesses. Table 1 contains a summary of the types of diagnoses that these children are likely to have. The goal is to identify children that are newly diagnosed with life-threatening conditions, in the mid-stage of their life-threatening diagnoses, and at the end of their lives (death anticipated within six months). The program will be available at selected sites throughout Florida and the targeted enrollment is 150 children. Of these children, 50 will be newly diagnosed, 50 will be in the mid-stage of their life-threatening illness, and 50 will be at the end-of-their life. These children will be in the intervention group.

Participation in the program is optional for families. Therefore, information will be gathered to the extent possible about families who decline to participate in the program. At a minimum, the following information will be available for all families regardless of their participation in the PIC: family/caregiver income, household size, child age, child gender, diagnoses, stage of the life-threatening illness (i.e., newly diagnosed, mid-stage, end-of-life), and health care use and cost for inpatient, outpatient, emergency room and pharmacy services. See the following paragraphs on *Data Sources and Measurements*. Families who do and do not participate will be compared on the preceding measures to determine if there are significant differences between the two groups.

In areas of the state where the program is not available, 150 matched controls will be selected to serve as the control group. The evaluators will work with the CMSN Care Coordinators and the children's physicians to select children that have the same or similar diagnoses, similar ages, the same gender, and the same life trajectories. These families will be asked to participate in interviews about their children's health care and will be told that the goal of the interview is to improve health care for children with serious conditions in the future. Because participation for this group is also voluntary, those who refuse to participate will be compared to those who do using the same measures described above.

D. Data Source and Measures

Health Care Use Measures

Several data sources will be used. First, enrollment and claims and encounter information will be available for all children in the intervention and control groups (as well as the groups who refused to participate). The enrollment files contain information about the children's age, gender, and family/caregiver income. The claims and encounter files contain diagnostic information recorded at the time of all health care service encounters, information about the type of care provided (outpatient visits, laboratory services, procedures, and others), the location of care (inpatient, outpatient, emergency room), information about filled prescriptions, and paid amounts for the claims. This information will be used to construct inpatient, outpatient, emergency room, and pharmacy use rates and cost for each of the children. In addition, the programs delivering the hospice care to the children have agreed to keep detailed records about support services delivered such as counseling services.

The Ambulatory Care Groups (ACGs) will be used to characterize the children's illness burden. The ACGs were developed at Johns Hopkins University and categorize diagnoses assigned at the time of health care encounters into groups according to their expected resource consumption and long-term implications. Children are assigned to a category that best classifies their resource consumption. The children's classifications based on this system will be used in the statistical models as a measure of their illness burden.

Child and Family/caregiver Functioning

Child and family/caregiver functioning and satisfaction will be assessed using telephone surveys administered to the respondent who is most knowledgeable about the children's health care (usually the mother) and when appropriate to the child. The following measures will be used:

1. The Pediatric Quality of Life Inventory (PedsQL) – The PedsQL is a modular instrument for measuring health-related quality of life (HRQOL) in children and adolescents ages 2 to 18. The PedsQL measures physical, psychological, and sociological functioning. In addition, there are modules that assess pain, nausea, procedural anxiety, treatment anxiety, worry, cognitive problems, perceived physical appearance, and physician/nurse communication. A parent report and child versions are available for use.¹
2. The Child Health Questionnaire (CHQ) – The CHQ is designed to comprehensively measure children's physical and psychosocial well-being and contains 11 subscales. Two of the subscales will be incorporated into the questionnaire: Family/caregiver Activities and Family/caregiver Cohesion.² These subscales measure the impact of the child's physical and psychosocial functioning on the amount of time the family/caregiver can spend together and how much stress the family/caregiver is experiencing related to the child's health needs.
3. Holroyds Questionnaire on Resources and Stress – This instrument is designed to assess caregiver stress and contains five subscales that will be used in this study. These are: dependency and management (the extent to which the child is dependent and difficult to manage), personal burden (the extent to which the primary caregiver feels burdened by child care), limits on family/caregiver opportunities (the extent to which child care limits other activities of family/caregiver members), family/caregiver disharmony (conflict), and financial stress. This

¹ Varni J, Seid M, Kurtin P. PedsQL 4.0: Reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care*. 2001; 39(8): 800-12.

² Landgraf JM, Abetz L, Ware JE. The CHQ User's Manual. First Edition. Boston MA: The Health Institute, New England Medical Center, 1996.

instrument has been used to assess caregiver stress when caring for children with severe illnesses.³

4. Family/caregiver Satisfaction - Selected items from the Consumer Assessment of Health Plans Survey (CAHPS) will be used to assess family/caregiver satisfaction with health care. In addition, items will be included to assess families' perceptions of their children's unmet health care needs; out-of-pocket spending for their children's health care; satisfaction with care coordination; and pain management. Selected items from the Child Core Medicaid Version of the CAHPS will be used with supplemental questions designed for children with chronic conditions. The evaluators developed the unmet need and out-of-pocket spending items based on similar items found in the National Health Interview Survey and the Medical Expenditure Panel Survey. The evaluators' items have been used since 1995 in over 7,000 surveys and currently are being used in a study funded by the Agency for Health Care Research and Quality designed to examine the quality of adolescents' health care in a State Children's Health Insurance Program (SCHIP).⁴

5. Child Interviews - In addition, a random sample of 30 families in each group who have children between the ages of 11 and 19 years will be asked if their children may complete the PedsQL, selected items from the CAHPS, and a short structured interview about their health and health care. Obtaining the adolescents' perspectives on their care is essential. Due to the sensitivities in talking to adolescents, particularly those with life-threatening illness, these adolescent interviews will be face-to-face.

The data from these adolescent interviews will be considered pilot data and will form the basis for further studies about end-of-life care for adolescents and their families. Based on the literature and the fact that some of those requiring end-of-life care will be adolescents, it is expected that 30 adolescents from each of the groups will be available to participate. If we do not achieve the desired sample size, these data are pilot data only and will still provide a very important basis for future work.

6. Hospice Care – The evaluators will work with the overall project team to select an instrument that is appropriate to assess families' satisfaction with hospice care. There are several toolkits available to measure end-of-life care.^{5,6} Each of these will be reviewed to select the most appropriate instrument.

³ Walker LS, Ford MB, Donald WD. Cystic Fibrosis and Family/caregiver Stress: Effects of Age and Severity of Illness. *Pediatrics*. 1987; 79:239-246.

⁴ Shenkman E, Vogel B. Access to and Quality of Care for Adolescents in SCHIP. Funded Agency for Health Care Research and Quality.

⁵ Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-Focused, Family/caregiver-Centered End-of-Life Medical Care: Views of the Guidelines and Bereaved Family/caregiver Members. *Journal of Pain and Symptom Management*. 2001. 22(3):738-751.

⁶ Toce SS, Andresen E. The Role of Data Collection, Evaluation, and Research in Pediatric Palliative Care. The Care of Dying Organization: Supportive Voice.

Table 1. Possible Diagnoses for Children Entering the Partners-in-Care Program

Category	Diagnoses
Neuromuscular	Brain and spinal cord malformations
	Central nervous system degeneration and disease
	Infantile cerebral palsy
	Epilepsy
	Muscular dystrophies and myopathies
Cardiovascular	Heart and great vessel malformations
	Cardiomyopathies
	Conduction disorders and dysrhythmias
Respiratory	Respiratory malformations
	Chronic respiratory disease
	Cystic fibrosis
Renal	Congenital anomalies
	Chronic renal failure
Gastrointestinal	Congenital anomalies
	Chronic liver disease and cirrhosis
	Inflammatory bowel disease
Hematology and immunodeficiency	Sickle cell disease
	Hereditary anemias
	Hereditary immunodeficiency
	Human immunodeficiency virus disease
Metabolic	Amino acid metabolism
	Carbohydrate metabolism
	Lipid metabolism
	Storage disorders
	Other metabolic disorders
Other Congenital or Genetic Defect	Chromosomal anomalies
	Bone and joint anomalies
	Diaphragm and abdominal wall
	Other congenital anomalies
Malignancy	

E. Data Collection Steps

All parents participating in the intervention and control groups will be interviewed upon program entry (or enrollment into the control group) and 6 months later. The 6 month interval is necessary particularly for those children at the mid-stage to end of life. If the study were to continue beyond one year, an interview at 12 months post-enrollment is recommended for those families and children who are still enrolled. Health care use rates and cost information will also be calculated at 6-month intervals for both groups. Pending the availability of funding, the evaluation is intended to extend over a four-year span in order to add data from statewide expansion of PIC and to identify trends, forecasting and predict out-year savings.

F. Data Analysis

Data will be analyzed descriptively to examine relationships among the variables first. Statistical models will be developed to answer the research questions listed above.

VII. Training and Outreach

A. Physician Training and Outreach

Informing primary care and specialty care physicians about PIC is critical to the success of the program. All PIC children and youth have a primary care physician who is responsible for providing or authorizing all services. The primary care physician is board certified in pediatrics or family medicine. In addition CMSN children and youth with special health care needs usually have one or more specialty physicians. The primary care physician is responsible for referring families to PIC, however the specialists may refer with the approval of the primary care physician. The family/caregiver, the care coordinator or the physician may make a referral. In all instances, the care coordinator will coordinate enrollment into PIC.

CMS will develop a physician outreach and referral plan that will acquaint primary and specialty care physicians within the CMS Network with PIC services. Information will include the identification of support services that will be available, how and by whom the services will be provided, the purpose of the services, the coordination of the services and how the physician will be informed of service outcomes. The referring physician must be fully informed about PIC services when talking with families about the availability of the support services.

In addition, CMS and hospice will work in collaboration to develop sensitive and caring information for families that are referred to PIC. Given the differences in the eight geographic areas, the eight sites will develop their own information and referral strategies that will be included in their Implementation Plan.

B. CMSN / Hospice Specific Training

Training is an important component of an access and marketing plan. A variety of training initiatives will be instituted. Each hospice and Children's Medical Services office will receive and will continue to provide training for their employees based on a defined curriculum. The PIC training curriculum will dovetail with the CHI/PACC curriculum currently being developed. Involvement in the CHI review process will enable Florida to build state specific modules that will complement the core CHI /PACC curriculum. It is anticipated that Florida will participate in the formative evaluation of the CHI curriculum in 2003.

All eight hospice programs involved in this waiver demonstration project must be properly trained in order to be fully prepared to provide PIC services to ill children and their families. A coordinated systematic training effort and curriculum will ensure that the same training curriculum will be provided to all eight-hospice programs and that new employees will receive the training. Consistent training will also ensure that all eight programs offer the same services to PIC recipients. The eight hospice programs will continue to receive information regarding subsequent training opportunities and may be included in training activities associated with PIC expansion. Additional training will be coordinated through Florida Hospices and Palliative Care as PIC expands statewide.

On-site training will be conducted at each of the eight hospice main service centers. All staff and volunteers providing care to ill children and their families will be required to attend all trainings. Additional training will be provided to program administrative staff to ensure adequate supervision, billing and data collection. It is anticipated that some of the curriculum will be for all staff and some components of the training may be specific to either CMSN or hospice. The training curriculum will be developed by FHPC in coordination with DOH/CMSN.

Training for direct service staff and volunteers in CMS and hospice will include but is not limited to the following topics:

- ✓ Psychosocial factors of seriously/terminally ill children
- ✓ Child development, with emphasis on different levels of cognitive ability
- ✓ Family/caregiver systems (with a focus on the extended family/caregiver)
- ✓ Spiritual care issues with seriously ill/terminally ill children
- ✓ Anticipatory grief and bereavement
- ✓ Introducing volunteer services to families
- ✓ How and where to refer families for additional services
- ✓ CMS service delivery system
- ✓ Care planning with CMSN staff
- ✓ Knowledge of research instruments including quality of life tools and program evaluation
- ✓ Pediatric Hospice Standards (AAP and CHI)
- ✓ PIC model
- ✓ How to provide care to children concurrently receiving curative care
- ✓ Differences in family/caregiver behavior and support when curative care is primary motivator
- ✓ Emotional transition and support for families when curative care is not attainable

Administrative training will include the following:

- ✓ Program development; how to include care of children into an adult hospice program
- ✓ Building collaborative relationships with other pediatric health care organizations
- ✓ Interviewing and hiring qualified pediatric staff
- ✓ Enhancing relationships with the local children's hospital
- ✓ Pain and symptom control
- ✓ System development to care plan/communicate with CMS
- ✓ Implementation of new billing procedures and tracking utilization
- ✓ On-going training and support of pediatric staff
- ✓ Knowledge of research instruments including quality of life tools and program evaluation

Children's Medical Services PIC training topics include but are not limited to:

- ✓ Overview of PIC Model
 - History
- ✓ Overview of Florida PIC model
 - Administration
 - Waiver Requirements
 - Eligibility
 - Enrollment
 - Financing
 - Evaluation/Outcomes
- ✓ Operationalizing the PIC Model
 - CMS Roles and Functions
 - Hospice roles and functions
 - Care Coordination Process
- ✓ Discussion of PIC Services
 - Respite Care
 - Individual and Group Counseling
 - Bereavement Counseling
 - Palliation Consultation
 - Volunteer Services
 - In-home Nursing and/or Personal Care
- ✓ Process for Coordinating PIC Services
 - Policies and Standards
- ✓ Payment for PIC Services
- ✓ Eligibility, Enrollment, Transfer and Disenrollment
- ✓ Hospice Overview
 - Philosophy and Structure
 - Reimbursement
 - Services
 - Staffing
 - Pediatric Hospice Standards
 - Licensure
 - Adult vs. Pediatric Hospice Care
 - Curative vs. Palliative Care

VIII. Advocacy and Family/Caregiver Centered Care

Title V is charged with the delivery of family/caregiver-centered care. This includes care that is culturally sensitive, community-based, coordinated and compassionate. To this end, the CMSN has hired in the past a full-time parent consultant to work with the program in developing marketing materials, policies, programs, and all forms of communication with the public that are family/caregiver centered. In addition, annual monitoring of the CMSN offices includes a formal assessment of family/caregiver-centered indicators, focus groups and formal reporting. Currently, the CMSN has a formal contractual relationship with the Florida Institute for Family/caregiver Involvement (FIFI); a HRSA/MCH funded demonstration project for these services. In addition, the CMSN is funding a full-time parent consultant for each of the 22 service area offices to serve as a liaison, support, educator and advocate for families enrolled in the CMSN. Contractual requirements include parent consultant participation in the annual office Quality Management Reviews, including parent focus groups and a family/caregiver-centered care report card that is included in the formal monitoring report. Additionally, FIFI was one of six

community- based organizations to receive federal funding through HRSA/MCHB for a Family-to-Family Health Information and Education Center for Families of Children and Youth with Special Health Care Needs.

Under contract with the CMSN and through a coordinated effort at the federal level (HRSA/MCHB), FIFI publishes a quarterly informational newsletter for the state's families who have children and youth with special health care needs. This publication, *Special Addition*, serves as a means for both state and federal communications with families. The Maternal and Child Health Bureau in HRSA provides states with the federal news and states add their specific information. PACC was featured in the February 2001 edition: <http://www.cms-kids.com/CMSNNetwork/SA 2-01final.pdf>

PIC articles are also scheduled for September and November 2002 issues to keep families apprised of the program and the waiver. For a comprehensive view of the Florida Institute for Family/caregiver Involvement, visit their website at www.fifionline.org

The PIC program has a formal planning and partnering relationship and agenda with FIFI to inform families and parent consultants about PIC and to ensure that the project is family/caregiver centered and represented by families in all aspects of planning and implementation, including model and waiver reviews.

IX. Quality Management Review

Quality management for PIC includes a formal, joint administrative and program review by AHCA, CMSN and FHPC. CMSN and FHPC will review program plan implementation activities specific to each program as noted in the Implementation Plan submitted by the demonstration sites. Each demonstration site will be reviewed no later than twelve months subsequent to implementation and at a minimum of annually thereafter. A combined QM report will be developed within 45 days of the site visit and distributed to the PIC site and the partner programs.

The review will include but not be limited to the following:

- ✓ Program Plan implementation
- ✓ Information and referral process
- ✓ Care coordination process
- ✓ Open case management process
- ✓ Patient record review process
- ✓ Grievance and Complaint Log review (including any fair-hearings)
- ✓ Advisory Council operations and issues
- ✓ Review of parent and provider satisfaction information
- ✓ Appropriateness of service
- ✓ Review of utilization
- ✓ Best practices
- ✓ Issues of Concern

Oversight and record review of the CMSN and PIC overlay services will include the following activities:

(a) Referral to PIC

- ✓ Assessment and documentation of information and referral regarding PIC services to the referring medical community.
- ✓ Review process and documentation for initial referral to PIC by physician.
- ✓ Review process and documentation for initial contact with family/caregiver regarding PIC.
- ✓ Review process and documentation for initial referral to hospice for PIC assessment.

(b) Care Coordination

- ✓ Review documentation of joint care plan meeting with hospice.
- ✓ Review the CMSN Care Coordination Plan for inclusion of hospice services including frequency, scope and duration.
- ✓ Review documentation of regularly scheduled staffings with hospice regarding PIC children.
- ✓ Review documentation of changes in PIC status (e.g. transfers, discharges, closure)
- ✓ Review of sample of CMSN medical records of children receiving PIC services for documentation of care coordination efforts that include the physician, the family/caregiver, hospice and other resources and providers.

The Agency for Health Care Administration administrative review will include but not be limited to the following:

- ✓ Development of the monitoring plan.
- ✓ Safeguarding against unnecessary utilization through analysis of utilization, claims data and record review.
- ✓ Review of billing procedures.
- ✓ Coordinated monitoring in conjunction with CMS and FHPC.
- ✓ Development of joint monitoring report.
- ✓ Follow up with appropriate partner on any performance improvement issues to ensure compliance.
- ✓ Maintenance of contracts and agreements.
- ✓ Assurance of accountability for PIC.
- ✓ Review of Advisory Council minutes.

X. Advisory Councils

The success of the PACC program must include building coalitions with the various constituencies to have their support and commitment of the project. Given the importance of these councils, each of the eight sites will establish a local PIC Advisory Council that will serve in an advisory and marketing/outreach capacity to the local PIC program. The advisory councils will operate within the parameters of PIC standards, policies and procedures. The councils will provide PIC recommendations for change or enhancement to the PIC Steering Committee for action and to ensure that the continuity of PIC is maintained throughout the state. Each of the eight sites has the flexibility to create a council that meets the unique needs of that region. It is expected that local health care professionals and families will serve on the council. The council will not exceed 10 persons of whom a minimum of two persons is to be representatives of

families who have a child in PIC or who have experienced the loss of a child. The hospice and the CMSN will each have one voting member on the council. The local PIC program will staff the advisory council meetings but will not chair the meetings. The group will elect the chairperson.

XI. Long-Term Vision

The long-term vision for PIC includes planning for the following issues:

- Full need expansion in 8 pilot sites (Phase II)
- Statewide expansion to the Medicaid population (Phase III)
- Statewide consideration for expansion to non-Medicaid populations (Phase IV)
- Addition of telehealth capability (Phase II-IV)
- Continued evaluation, research, and training (Phases I-IV)
- Expansion of quality review (Phase II, IV)

Considerable planning and analysis of data obtained through the demonstration project must occur prior to be applied to PIC expansion. Phase II includes expansion to meeting full-need in the eight pilot areas since the demonstration is limited to 150 children. There are an estimated 1800 children eligible for PIC in the pilot areas. Phase II will begin after one year of the demonstration pending the outcome of the evaluation.

Medicaid expansion must also include children who are not enrolled in the CMSN, i.e. they have chosen a Medicaid HMO, MediPass, a disease management program or a Provider Service Network. Though this is a small population group, there are a variety of operational and policy issues that must be addressed prior to statewide expansion for the Medicaid population. Phase III is scheduled for implementation in the third year following implementation of the pilot program. An additional 2500 children are estimated to be eligible statewide for PIC following full need implementation in the pilot areas.

The CMSN is the required insurance plan for special needs children enrolled in the state's Child Health Insurance Program (CHIP/Florida KidCare). Children who meet the medical eligibility for children with special health care needs are enrolled in the CMSN. Based on demonstration project data pertaining to cost, utilization and satisfaction, PIC services could be added to the KidCare benefit package for children enrolled in the CMSN. Likewise, PIC could also be expanded to children enrolled in the CMSN Safety Net Program. These are children who do not qualify for either Medicaid or KidCare or who lose their benefits from either plan, who are underinsured, or whose estimated cost of care will reduce their income to a level meeting the financial requirements for the CMSN. Estimated expansion of Phase IV-PIC is in year four following implementation of the pilot project.

Telemedicine is a major component of the CMSN and includes opportunities for adding distance specialty clinics, consultations as well as a means to establish or maintain communications between families, providers and care coordinators. There are several ways that PIC could benefit from tapping in to the CMSN telemedicine network, including pediatric palliative care consults. The PIC Steering Committee as well as the local PIC Advisory Councils would be instrumental in identifying ways to apply telemedicine to PIC. A full description of the current use of Telehealth in the CMS is available on the web at the following address: <http://www.cms-kids.com/Telehealth.htm>. It is anticipated that discussion regarding the use of telemedicine will

occur and evolve during the implementation of the pilot program in Phase I of the project and continue through Phase IV. Initial discussions will begin in Phase 1 with pilot usage in Phase II.

PIC evaluation is critical to PIC expansion. Expanded PACC funding or specific funding grants will be necessary to guide and support PIC expansion through Phases II -IV. Application for research grants through local universities and other funding programs that support end-of-life programs may be required to fulfill the vision for expanded PIC services.

As PIC expands, the need for training will increase. The training curriculum needs to evolve into a responsive and effective agent of change over time. As new curricula are developed, they need to be reviewed and integrated into the PIC curriculum as appropriate.

Monitoring through annual quality reviews of PIC programs will be an increasing, work intensive process as the program expands. As a result of the demonstration project, planning for long-term, comprehensive monitoring and annual reviews of PIC to ensure quality is critical to the success of the program. Cost estimates for accomplishing this task as well as other options must be explored.

XII. Baseline Data

Attachment I contains Medicaid hospice claims data that are predominantly adults. Attachment II details the care coordination process that will drive the coordination of PIC services between the CMSN and hospice. Attachment III contains a summary of four years of related Medicaid claims data for the CMSN (0 to 21 years of age). Claims data are broken down into demographics, expenditures by service and by diagnostic categories.

ATTACHMENTS:

- I. MEDICAID HOSPICE DATA
- II. CARE COORDINATION GUIDELINES
- III. FOUR YEARS OF CMSN UTILIZATION DATA- (1994-1999)